Chapter

Psychosocial Aspects of Glaucoma

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Abstract

Glaucoma, not only leads to irreversible visual impairment, but also has a negative impact on Quality of Life of the patients. Visual disability, lifelong medical and surgical treatments and even the mere knowledge of having an irreversible potentially blinding condition tend to cause severe psychological stress in patients, leading to negative emotions such as anxiety or depression. The goal of glaucoma treatment should not be limited to preserving the vision, but also address the psychological aspects and preservation of patient wellbeing. Patient counselling, right from at the time of diagnosis, periodic psychological assessment and creating awareness in the society as a whole should be implemented as a part of holistic approach to glaucoma. Utilisation of Patient- reported quality of life tools would help clinicians in more closely understanding the problems and would, in turn, aid in providing comprehensive customised treatment option for each patient.

Keywords: Glaucoma, psychosocial impairment, Quality of life, Patient counselling

1. Introduction

Glaucoma is a chronic progressive optic nerve disease that can potentially lead to blindness, if left untreated. It is the second most common cause of blindness and the leading cause of irreversible blindness worldwide [1]. Global prevalence of glaucoma has been estimated to be 3.54%, though geographic variations exist. Incidence of Primary open angle glaucoma has been found to be highest in African countries, while that of primary angle closure glaucoma in Asian populations [2]. Presently, 80 million people are affected with glaucoma, worldwide. This number is expected to rise to almost 111 million by the year 2040 [2, 3]. However, these numbers may just be reflecting the tip of the iceberg. Owing to slow and silent progression, the disease remains undiagnosed in many individuals till fairly advanced stages. Diagnosis is often delayed and approximately 40% of retinal nerve fibres are lost by the time field defects could be appreciated on standard White-on-White perimetry [4]. Moreover, the disease characteristically involves peripheral and mid peripheral visual fields initially, which may go unnoticed in many patients. Elderly population is at a greater risk as they tend to ignore it as an age-related inevitability [5]. Unfortunately, at the time of first presentation, most patients have significant irreversible peripheral visual field defects. This is truer for population residing in developing and underdeveloped countries, with less awareness and limited access to basic eyecare services. Some of the earlier epidemiologic studies conducted in West Indies, [6] Australia [7] and Netherlands [8] reported more than 50% patients having undiagnosed glaucoma during screening. Data from Indian studies reported an even higher proportion of undiagnosed cases discovered during screening [9–11].

World health organisation (WHO) has defined Quality of life as "individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." [12]. In other words, it can be defined as an individual's own measure of various life conditions experienced by him, including physical health, mental and psychological health, dependency, social functioning and economic wellbeing. Thus, conditions affecting any or all of the above-mentioned aspects, would hamper Quality of life. Glaucoma not only causes permanent visual disability, but also has a negative influence on mental and psychological health, which is subjective and individual specific [5]. Individuals with glaucoma tend to develop negative emotions such as anxiety or depression, which are detrimental in the daily functioning and wellbeing. With the number of glaucoma cases projected to rise, the psychosocial aspect of glaucoma is now becoming a global concern for clinicians all over.

2. Factors affecting quality of life in glaucoma

2.1 Disability due to visual field defects

Glaucoma causes irreversible defects in the visual fields, that are slow and progressive. Glaucomatous visual field defects appear to be non-specific and follow the pattern of retinal nerve fibre layer loss [13]. Initially, the disease involves peripheral fields and tends to go unnoticed, till the time it progresses to involve central and paracentral areas. Hence, it is less common for an individual with early glaucoma to present with visual symptoms. Although, some individuals, particularly those involved in driving or sports, may notice these peripheral field defects rather early. Typically, by the time a patient presents with visual symptoms, significant field defects have already set in. With progression of the disease, patients find it more and more difficult to pursue day to day activities. They find themselves bumping into objects while walking, as they are unable to perceive obstacles in the path which lie in the non-seeing areas of the visual field. In advance stages, blindness ensues causing complete dependency even for performing routine tasks. Studies have demonstrated that beside visual fields, glaucoma also affects other visual functions such as contrast sensitivity and dark adaptation. Impairment of these functions can further compound the problems for the patients. Activities such as night time driving, that require good peripheral vision with dark adaptation and contrast sensitivity, become difficult to execute. All these factors cause significant visual disability among patients, even in moderate stages of the disease. Difficulty in carrying out daily activities and fear of falling increases dependency and limits social functioning [14]. This causes a negative effect on patients' thought process, and directly impacts their mental health. It is evident through various studies, that deterioration of Quality of life and mental health status is associated with the worsening of visual impairment in glaucoma [15–17].

2.2 Adverse effect related to treatment

Intraocular pressure is the only known modifiable risk factor known for glaucoma [18]. Hence the current treatment options aim at reducing the intraocular pressure. This can be achieved either by medications, laser treatment or filtration surgeries. Conventionally medical management, by the use of topical or systemic intraocular pressure lowering agents, is considered as the first line therapy. Monotherapy with one agent or a combination of two or more agents may be required to achieve the target intraocular pressure, depending on the severity of

disease. Here we briefly discuss some of the commonly prescribed topical medication and related adverse effects:

Prostaglandin Analogues (e.g., Latanoprost, Bimatoprost, Travoprost): Preferred as first line agents in glaucoma patients. They lower the intraocular pressure most effectively, with once daily dosing, by facilitating the uveoscleral outflow. Prostaglandin analogues do have several associated ocular side effects including darkening of iris colour, trichomegaly (eyelash growth), periocular skin pigmentation, conjunctival hyperaemia and cystoid macular edema.

Beta adrenergic blockers (e.g., Timolol, Betaxolol, Levobunolol): One of the most commonly used drugs as first line therapy. It reduces the production of aqueous humour by acting on the ciliary body, inhibiting beta adrenergic receptors. Effects may be lost in time due to tachyphylaxis. In addition, it can be associated with local and systemic side effects such as bradycardia, bronchospasm, hypoglycaemia, depression, dry eye, punctate keratitis. Ocular stinginess is associated with betaxolol.

Alpha adrenergic receptor agonist (e.g.: Brimonidine): It is potent class of antiglaucoma agents used as first line therapy. It is recommended mainly for chronic use in patients with concomitant cardiopulmonary disease or any other contraindications to beta-blockers. Adverse effects include allergic conjunctivitis, conjunctival hyperaemia, pruritis, dry eye, fatigue and drowsiness.

Carbonic Anhydrase inhibitor (e.g.: Dorzolamide, Brinzolamide): It is derivative of sulphonamide, which decreases the production of aqueous humour. After corneal penetration, it inhibits the carbonic anhydrase in the ciliary body, slowing local bicarbonate production which in turn decreases sodium and fluid transport, thus reducing aqueous humour secretion. It can precipitate corneal edema with patients with decompensated cornea. Other ocular adverse effects include stinging sensation, metallic taste in mouth after instillation and granulomatous anterior uveitis (rare).

All the topical agents have potential to cause localised ocular adverse effects that can cause discomfort to the patient. Moreover, many of the intraocular pressure lowering agents require more than once daily dosing schedule, that elderly patients might find tedious or difficult to follow. Apart from the ocular and systemic effects of the topical medications, problems associated with preservatives present in the preparations, on ocular surface, should be borne in mind. Preservatives are additive agents added to extend the shelf-life of an ophthalmic preparation. Commonly used preservatives include Benzalkonium chloride (BAK), Purite, parabens, chlorobutanol, sodium chlorite, and a boric acid plus D-sorbitol plus zinc chloride fixed combination. However, these preservative agents are known to destabilise the cell membrane, causing cell loss and reduced cell surface adhesions, in normal corneal and conjunctival tissue. This may give rise to various ocular surface diseases, including superficial punctate keratitis with corneal erosions, papillary conjunctivitis, dry eye, low tear film break-up time, conjunctival injection and anterior chamber inflammation.

Treatment for glaucoma requires lifelong instillation of intraocular pressure lowering medications. Chronic instillation of these medications over a period of time can accentuate insult to the ocular surface. Recent studies have demonstrated cellular level changes, including epithelial thickening, loss of goblet cells and conjunctival stromal thickening, associated with long term use of antiglaucoma medications [19]. With altered ocular surface structure, the tear film function gets compromised resulting in conditions such as dry eye syndrome and conjunctivitis medicamentosa. Prevalence of ocular surface disease has been estimated to be 59% in patients with glaucoma, with medication playing a significant part [20]. Ocular surface disease was found to have a negative impact on patient reported quality of life scores, with majority reporting ocular pain and discomfort [16, 21]. Although

preservative free preparations are now available in the market, which claim to be free from adverse effects of preservatives, further studies would be required to conclusively prove their superiority over the conventional preparations.

On the other hand, surgical interventions such as trabeculectomy or drainage device implant, though reduce the dependency on topical medications, come with their own disadvantages. These include intraocular pressure fluctuations, lifelong follow ups, need for secondary interventions such as antimetabolite injections, bleb needling or repeat surgery in case of filtration failure. Patients with surgical intervention reported more ocular discomfort, probably owing to the presence of conjunctival bleb on the ocular surface [22].

2.3 Psychological impact of diagnosis of glaucoma

As with other chronic diseases, diagnosis of glaucoma can be a stressful experience and a psychological burden for the patient. Even on just learning about the diagnosis, many patients develop negative emotions such as anxiety or depression. Given the potential blinding nature of the disease, bulk of the negative thoughts arise due to the fear of going blind. Moreover, factors such as changes in daily routine, regular use of medications, lifelong treatment and follow ups can cause psychological stress. Studies done in recent decades have provided us with an insight into the patient thought process. In the Collaborative Initial Glaucoma treatment study, the newly diagnosed patients were found to have moderate to severe psychological fear of blindness at the time of diagnosis [23]. Odberg et al. reported negative emotions in almost 90% of newly diagnosed cases of glaucoma [24]. This psychological stress may be partly attributed to lack of awareness about the disease in general population. Patients tend to misinterpret the diagnosis of glaucoma as that of impending blindness. They are totally unaware of the treatment options available, and the fact that the disease progression can be retarded or halted with the use of various medical and surgical modalities. Poor disease comprehension has shown to be negatively associated with psychological and quality of life scores [25]. It should be borne in mind that patients can develop psychological emotions such as anxiety and fear of potential outcomes irrespective of duration of disease.

2.4 Financial and economic perspectives

Glaucoma, being a chronic disease, can become a financial burden for the patients. Cumulative cost of treatment over many years- whether medical or surgical- can be a major problem for patients. A significant proportion of patients reside in middle to low-income countries, with low per capita income and lack of government funded social security schemes, affordability of treatment may be a challenge for them in the long run. These patients have to spend a large share of their monthly income on treatment for glaucoma. A single follow up visit to the hospital leads to financial loss to those employed as daily wage workers. For people residing in remote areas with inadequate health facilities, even travelling all the way for a follow-up visit is a herculean task. All these factors play a significant role in patients not adhering to treatment and follow-ups. As the disease progresses and visual fields deteriorate, patients find themselves at a constant risk of loss of livelihood. With loss of livelihood, and limited or no other sources of income, continuing treatment of glaucoma becomes virtually impossible.

Hence it is evident that glaucoma associated psychosocial impairment is multifactorial, and not just caused by loss of visual function alone. Psychological and financial factors play an equal role in determining the quality of life of a patient. In recent decades, much attention has been drawn towards assessment of the

psychological effects of glaucoma, in an attempt to preserve social wellbeing of the patients. Population based cross sectional studies have been conducted in both developed as well as developing and underdeveloped regions. Studies conducted in Singapore, [26] China, [25] Japan, [17] India, [15, 16] Germany [27] and Nigeria [28] have brought forth the conclusion that glaucoma does have a deleterious effect on patient psychology, mental health status, social functioning and above all quality of life. The quality of life of deteriorates as the disease progresses, owing to worsening of visual fields, limitation of social functioning and increased dependency. Significant prevalence of anxiety and depression in patients with glaucoma reflects the enormous psychological burden of the disease [26, 27].

3. Management- what needs to be done?

Earlier, management for glaucoma was aimed only at preserving the visual function by control of intraocular pressure. Less emphasis was given to psychological impact of the disease as well as its implication on quality of life of the patients. Today, with the data from various studies, we now know the mental, social, financial and psychological implications of the disease. Considering the prevalence of glaucoma, the magnitude of problem is tremendous. Hence, mere treatment of raised intraocular pressure may not be sufficient. One should aim at providing a decent quality of life and preserving patient wellbeing. It should be borne in mind that one should treat the patient and not just intraocular pressure.

3.1 Patient counselling

It has been demonstrated that disease comprehension is often poor among patients, causing psychological stress and feeling of despair and panic. Counselling of patients about the disease can help alleviate this problem to some extent. Counselling should be started right at the time of diagnosis, by the treating clinician and continued on periodic basis over the course of treatment. Patients should be made aware about the disease, treatment options available for them, importance of treatment compliance and periodic follow-up. This would help in alleviation the psychological fear, as shown by Odberg et al. in their study [24]. During the course of treatment, patients may require periodic motivation to adhere to the treatment and follow ups.

3.2 Assessment of psychological state and quality of life

A qualitative or quantitative assessment of psychological state of the patient should be included as a part of glaucoma management. This can be performed with the use of various tools in the form questionnaires. Some of the commonly available tools are mentioned in **Table 1**. These questionnaires can be either generic (Short Form-36) or vision specific (NEIVFQ-51, NEIVFQ-25) or disease specific (Glaucoma Quality of Life –15, Glaucoma symptom scale). Although any of the above-mentioned tools can be utilised as per convenience, Patient reported outcomes (PRO) have been more commonly used tools. PRO based questionnaires provide a better perspective of the difficulties experienced by the patient. Apart from quality of life, separate instruments are available for measuring negative mental conditions-precisely anxiety and depression. Some of the tools such as Hospital Anxiety and Depression scale (HADS), General Anxiety Disorder-7 (GAD-7) are easy to use and can be self-administered in the clinic or at home. As with counselling, such assessment should be done at the time of diagnosis and periodically during follow ups. Any deterioration in the scores would warrant need for intervention such as counselling.

Name of questionnaire	Brief Description
National eye institute visual function questionnaire –25 (NEIVFQ-25)	25 -item questionnaire measuring vision dependent functioning and influence of vision problems on quality of life. Measures various patient reported functions including general health, mental health, social health, dependency, driving, near vision, colour vision, ocular pain etc. All these sub scores are used to calculate composite score. It measures Patient reported outcomes (PRO)
Glaucoma Quality of Life –15 (GQL-15)	It's a disease specific questionnaire. Assesses only vision related difficulty, taking into account the effect of binocular visual field loss on visual function.
Short Form-36 (SF 36)	Short general health questionnaire. Assesses the physical component, mental health, emotional- role and social functioning. It was used to measure quality of life in Ocular hypertension treatment trial.
World Health organisation BREF (WHO-BREF)	It is the shorter version of the original 100 item questionnaire. Measures General health, positive feeling, social support, financial resources/ physical, psychological and social relationships

Table 1.
Brief description of some commonly used validates questionnaires for assessment of quality of life.

It should be kept in mind that individuals with poor quality of life scores or negative emotions are susceptible to treatment non-compliance. Hence it is essential that the treating clinicians remain aware of the psychological condition of their patients.

3.3 Vocational training

Visual disability becomes profound as the disease progresses to advanced stages. Apart from causing limitations in social functioning, it can lead to loss of livelihood. This may be detrimental to patient's quality of life causing low self-esteem and frustration. In such scenarios, vocational training and use of low vision aid devices can be beneficial for many patients. Use of low vision devices such as magnifiers, telescopes or field expanders can help patients in utilising their residual field of vision. Vocational training activities would help them with performing routine tasks independently. Moreover, they can learn newer skills that may generate livelihood opportunities for some. These activities can provide patients with much needed self-confidence, reduce dependency and would aid in improving Quality of life to some extent.

3.4 Creating awareness among general population

With constant rise in number of people with glaucoma, there is a need to create awareness about the disease among the masses. Sensitising the community regarding the disease, its treatment as well as about the problems faced by the patients would help in generating community- based support for patients with glaucoma. Such moral support from friends and family members would be beneficial for the patients in keeping themselves motivated while facing the challenges associated with glaucoma. Community based social groups for persons with glaucoma should be promoted, wherein patients can share their experiences and problems.

4. Conclusion

Patients with glaucoma are prone for developing psychological disturbances that in tun negatively affect quality of life. Apart from visual disability, psychological

effect of diagnosis, treatment related adverse effects and financial issues play an important role in hampering the quality of life. A comprehensive approach consisting of patient education, psychological assessment, motivational counselling and vocational therapy should be adopted as a part of glaucoma management protocol. This would enable clinicians to provide customised holistic treatment for each patient, thereby increasing compliance and providing better quality of life.

Conflict of interest

The authors declare no conflict of interest.

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